

Transforming social care: sustaining person-centred support

Findings
Informing change

May 2011

The Standards We Expect project offers the first in-depth examination of the development of person-centred support, or 'personalisation', from the perspectives of service users, carers, face-to-face practitioners and middle managers. Working with a diverse range of service users across many different health and social care settings, it explores what person-centred support means to people, how to develop it effectively, what barriers it faces and how these might be overcome.

Key points

- Service users and practitioners strongly agree on the definition of person-centred support. They identify clear, value-based criteria for what it must mean to be helpful. Commitment to these values is seen as crucial for real change. Such person-centred support is highly rated and supported by most practitioners and service users.
- Much mainstream discussion about personalisation has focused on methods and techniques rather than the objectives of achieving person-centred outcomes. It has been tied to the structures and constraints associated with traditional policy and provision limiting its effectiveness and reducing support for it.
- Practitioners and service users are working hard to advance person-centred support in many settings, developing bottom-up ways of challenging barriers. However, there is evidence that a range of substantial barriers is seriously impeding the long-term sustainability and widespread application of person-centred support and putting it at risk.
- The inadequate funding of social care and negative aspects of its culture underlie these barriers. These encourage institutionalisation, poor quality provision, inequity and late intervention. As a result people's basic rights are often not being met. Achieving person-centred support emerges as inseparable from fundamental cultural and funding change.
- The conclusion from this project is that adequate funding from general taxation is likely to offer the most effective route to achieve 'person-centred support' and to reduce the increasingly unhelpful barriers between health, social care and other services.

The research

Carried out by the user-led
Standards We Expect consortium

Background

There is now widespread acceptance among service users, policy-makers, politicians and practitioners that existing social care policy, practice and funding are inadequate and untenable, particularly if they are to meet increasing needs predicted through major demographic and social change and medical innovation. Social care policy and funding are both currently under review.

What person-centred support means to people

*'It's not another job, it's **the** job. Person-centred support is not another thing that you have got to do, it is **what** you have got to do.'* (Practitioner)

A consensus definition of person-centred support emerges from the project, one that is consistent with ideas of 'person-centred planning' and 'independent living'. Both of these are concerned with putting in place the support people need to live their lives on as equal terms as possible with non-service users, rather than seeing service users as needing 'care' because of perceived deficits and pathologies.

Participants' definition of person-centred support is strongly based on values rather than techniques or procedures. Key components cited are:

- putting the person at the centre, rather than fitting them into services;
- treating service users as individuals;
- ensuring choice and control for service users;
- setting goals with them for support;
- emphasising the importance of the relationship between service users and practitioners;
- listening to service users and acting on what they say;
- providing up to date, accessible information about appropriate services;
- flexibility; and
- a positive approach, which highlights what service users might be able to do, not what they cannot do.

Barriers in the way of person-centred support

'You're going to the supermarket to do your shopping and it's something that everyone in the world does and you have to do a risk assessment on it!' (Practitioner)

Participants highlighted a range of major barriers which undermine person-centred support and restrict their rights. Not only does each of these create its own obstacles inhibiting such an approach, but combined they magnify such difficulties. Key barriers identified include:

- The lack of a well-supported, skilled and well-trained workforce and low levels of staffing. Generally, poor terms and conditions were associated with low retention and high turnover rates, offering little prospect of ensuring an adequate workforce to match predictions of greatly increasing demand.
- Increasing reliance being placed on family members as 'informal carers'. Without sufficient support for carers themselves or help for them to facilitate service users' independence, this provides an inadequate and inappropriate basis for meeting increased future need.
- The lives of many long-term and residential service users are restricted by continuing institutionalisation. This disempowers them, undermines their confidence, limits their potential and prevents them gaining the skills to live fuller, more equal lives.
- Organisational barriers to person-centred support. These operate at all levels. Participants cite increased bureaucratisation, tightening administrative controls, inflexible organisations, crude target setting and an emphasis on 'negative risk', often framed in terms of health and safety requirements.
- Social care practice. Participants saw this as following from a disempowering service culture that is still often paternalistic and inflexible – 'making unhelpful assumptions about what service users can and can't do,' as one said – and restricting the crucial relationship between them and practitioners.
- Service users' restricted access to mainstream policies and services, keeping them within social care services and undermining the holistic approach of person-centred support to live on as equal and inclusive terms as possible. Three particular areas mentioned were: travel and transport, education and continuing disability discrimination. People living in rural areas and from black and minority ethnic communities face additional barriers.
- Some barriers relate to service users' circumstances and experience. Many lack the support they need to be able to access and take advantage of person-centred support. There is a lack of capacity-building through ensuring accessible information, advice, guidance and advocacy.

Overcoming barriers

'It pushes you into being very creative as a worker – as long as your creative ideas are ... more cost-effective than other things.' (Practitioner)

Much is being done in local services to deal with these barriers. Some services, linking with users and carers, are working hard to overcome them. For example:

- supporting workers by demonstrating they are valued, providing good supervision, support and training and improving service user/staff ratios;
- supporting carers through increasing their involvement, providing information and offering opportunities for them to come together as well as developing advocacy and support for service users;
- supporting people in residential and segregated services to do things for themselves, seeing them as individuals, exploring their preferences for the future, encouraging them to learn from people already living more independently, working to involve them in change, providing training and capacity-building for both staff and service users and offering opportunities for service users to get together to increase their say and confidence;
- developing 'softer' more sensitive targets and measures consistent with independent living and person-centred support, exploring and prioritising 'positive' risk-taking and challenging assumptions of people's dependence and vulnerability;
- building relationships between service users and practitioners, supporting one-to-one working and adopting a flexible approach to practice, which matches with each person's unique needs and the rights they share with others;
- prioritising continuity, good communication and listening skills as key components for person-centred practice and supporting communication with people who communicate differently, both to ensure their inclusion and the development of relationships with practitioners;
- supporting service users to make informed choices, providing opportunities for capacity-building and offering assistance to negotiate mainstream and support services, through providing information, advocacy, service brokerage and direct payments/individual budget support schemes;
- recognising the importance of person-centred support schemes which address people's access to mainstream policies and services, particularly in relation to cultural and ethnic differences.

Continuing barriers to person-centred support

'All it is, is cutbacks, cutbacks or no money available.' (Service user)

However, the efforts on the ground to challenge barriers are not enough to enable person-centred support to become the norm for all service users. Barriers seem to be rooted in two major and inter-related problems: chronic inadequacy of social care funding and the continued existence of a social care culture at odds with person-centred support. This problematic culture is reflected in continuing institutionalisation, control, paternalism and inflexibility in services and reliance on a 'deficit' model rather than on the philosophy of independent living as the basis for providing support. Funding problems also lie at the heart of workforce inadequacies, over-reliance on unpaid carers, insufficient and inaccessible mainstream services and lack of suitable advocacy, advice and information services.

A series of additional problems created by inadequate funding emerged, including:

- rationing, restricting access to and undermining equity in support;
- uncertainty about future funding, resulting in short-termism in policy and provision;
- funding being used as an excuse for not making change;
- over-reliance on one-off projects and initiatives;
- discouraging early intervention and prevention;
- restricting the range of support available;
- requiring people to pay for social care and charging for support which perpetuates inequities, restricts access, undermines prevention and encourages institutionalisation;
- undermining service users' independence.

Conclusion

Making person-centred support sustainable

Present efforts to move to person-centred support are being undermined by social care's funding problems. It is difficult to see from this project how person-centred support can be rolled out and achieved for all on a sustainable basis for the future, without social care being securely and adequately funded. The conclusion from the findings from this project is that funding through general taxation is likely to be the most viable and effective way of achieving this. The unification of NHS and social care funding arrangements is also likely to help overcome arbitrary and unhelpful divisions between the two.

The importance of involvement

'They just come in and announce a change and there's not been any consultation on it and it's just introduced.' (Service user)

While there has been an increasing emphasis on user involvement in social care, in practice, service users' and practitioners' reports of user involvement are frequently negative and they see its impact as limited. However, they see user involvement as crucial to person-centred support and its development. They offer a basis for effective and inclusive involvement for the future.

So far policy and discussion about 'self-directed support' and personalisation have largely been located within traditional policy arrangements, rather than challenging them. The Standards We Expect project highlights that an effective approach to change to achieve mainstream person-centred support:

- is likely to require systemic change;
- will be rights-based and needs-led, in line with an independent living philosophy;
- can make some progress through bottom-up approaches, without broader reform, but this is likely to be limited, insecure and constrained;
- needs a stable context; the constant churn of organisational and external change makes it difficult to sustain bottom-up developments;
- needs commitment at every level;
- requires the development of forums for collective involvement and opportunities for capacity-building for all key stakeholders: these are key for participatory change to be possible;
- takes a long time, longer than might be expected.

Stakeholders in different, potentially conflicting, roles can collaborate and build shared views and understanding in such situations. Most people are pleased to be involved in making change. They welcome and value the opportunity. It is possible to involve a wide range of service users, practitioners and managers in change, if this is done in a supportive and accessible way.

There can be many different ways of achieving person-centred support, although some service approaches may be less supportive of it. Overall, the project highlights the importance of:

- a participative process of change, drawing on bottom-up approaches rather than simply top-down ones;
- a changed culture based on the philosophy of independent living;
- adequate funding for social care;
- serious reprioritising of social care by governments, politicians and policymakers.

About this project

The Standards We Expect consortium was a collaborative UK-wide research and development project, involving four organisations, including Shaping Our Lives, Values Into Action, the Centre for Social Action, de Montfort University and the Centre for Citizen Participation, Brunel University. It was made up of service users, researchers and practitioners and running over four years. It worked in eight sites with a broader network of 12 organisations and services. It included a very wide range of service users in a diverse range of social care, health and housing settings, providing a variety of support services, both urban and rural. It worked in a participatory way emphasising the involvement of service users, face-to-face practitioners and carers and exploring their ideas and experience about person-centred support. It offered participants a range of support for taking person-centred support forward in their localities, including information and guidance, collective forums, capacity-building and opportunities for shared learning (direct from the website).

Find out more

A book, **Supporting people: Towards a person-centred approach** by Peter Beresford, Jennie Fleming, Michael Glynn, Catherine Bewley, Suzy Croft, Fran Branfield and Karen Postle, ISBN 9781847427625, is available from www.policypress.co.uk, price £19.99 rrp (plus £2.75 p&p).

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Tel: 01904 615905 email: info@jrf.org.uk